TESTIMONY FOR A HEARING ON:

NURSING HOME QUALITY OF CARE AND PATIENT SAFETY AND ENFORCEMENT

PRESENTED BEFORE:

THE NEW YORK STATE ASSEMBLY COMMITTEE ON HEALTH
RICHARD N. GOTTFRIED, CHAIR

THE NEW YORK STATE ASSEMBLY COMMITTEE ON AGING
DONNA A. LUPARDO, CHAIR

PRESENTED BY:

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MOBILIZATION FOR JUSTICE, INC.

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I. Introduction

Mobilization for Justice’s mission is to achieve social justice, prioritizing the needs of people who are low-income, disenfranchised or have disabilities. We do this by providing direct civil legal assistance, conducting community education, engaging in policy advocacy, and bringing impact litigation.

Since 2011, Mobilization’s Nursing Home Residents Project has continued the work of Friends and Relatives of the Institutionalized and Aged (FRIA), which for 35 years provided information and advice to nursing home residents and their families. MFJ offers advice, counsel, and representation to nursing home residents in individual matters and impact litigation. We also provide training and educational sessions to nursing home residents, family members, and ombudsmen.

We thank Chairperson Gottfried and the Assembly’s Health Committee and Chairperson Lupardo and the Assembly’s Aging Committee for this opportunity to discuss the strict control that facilities exercise over residents, and the Department of Health’s failure to enforce regulations.

Over 40 years have passed since New York State enacted nursing home reforms following the Moreland Commission’s report of scandalously poor care. Thirty years ago, the federal government took a substantial step forward with the 1987 Nursing Home Reform Act (NHRA) and the resulting regulations at the state and federal level. Unfortunately, the promise of these reforms has not been realized.

More people live in nursing homes in New York than in any other state. There are more than 112,000 nursing home beds in this state – for comparison, almost a full Assembly district – and the overall occupancy rate is over 90 percent.1 Almost half of those nursing home beds are in New York City. There are more than 600 nursing facilities in the state and about 175 facilities in the City. Although some facilities advertise their “home-like” environment, any visitor to these facilities will recognize them as institutions. The average facility in New York has 180 beds, but many facilities, particularly in New York City, have many more: More than three quarters of nursing homes have 100 beds or more; dozens have more than 400.2

Much needs to be done to ensure residents receive the quality care, dignity, and self-determination the law requires.

II. Key Recommendations

Mobilization for Justice suggests a few legislative measures to improve oversight in nursing homes and ensure better quality care for residents:

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2 Id.
1. **Enact a staffing ratio bill to ensure high quality care.** New staffing data based on payroll data from New York nursing homes shows that most facilities do not provide residents with the staffing necessary to receive responsive and sufficient care. Without a statutory minimum, facilities will continue to skimp on staffing.

2. **Strengthen government oversight of nursing homes.** Increase the DOH’s funding for inspection and surveillance to hire more staff so investigations of complaints can happen in a more timely manner. Require the DOH to ensure compliance following all documented regulatory violations. Reduce the DOH’s discretion for issuing penalties, requiring more accountability.

3. **Ensure better enforcement of protections for residents facing involuntary discharge from nursing homes.** Improve training programs for administrative law judges at the DOH who preside over discharge hearings. Require the DOH to audit facilities’ records regarding residents whom a facility discharges or tries to discharge to a homeless shelter.

4. **Ensure nursing home residents are able to exercise their right to integration into the community.** Pass legislation revising the language of Public Health Law § 2803-c that would explicitly secure residents’ rights to engage with the community outside the nursing home. Federal and state law already give residents the right to leave facilities temporarily for social, religious, or other reasons, but unreasonably restrictive facility policies prevent residents from exercising that right, and the DOH refuses to review day pass denials. The legislature should ban overly restrictive policies, requiring a person-centered approach to foster community integration.

5. **Increase funding for the Long-Term Care Ombudsman Program and Legal Services.** Under federal law, nursing home residents have a right to services from the Long-Term Care Ombudsman Program, but New York’s lack of support for this program makes that impossible. In 2015, New York had a paid staff of local ombudsmen of 36.06 FTE. That’s one staff person for more than 4,426 institutionalized residents. New York is solidly in the bottom half of states by this metric. In California, which is 23rd, the ratio was about half: one full-time ombudsman staff person for 2,242 residents. New York’s Ombudsman Program is severely underfunded: Of all states and the District of Columbia, New York’s Ombudsman funding per nursing home bed is 48th, and its total funding per bed (including adult homes) is 46th. Increased investment in the Ombudsman Program would be money well spent to protect vulnerable New Yorkers. There are, however, some problems that the Ombudsman Program cannot resolve and for which nursing home residents need attorneys. There is a substantial need for legal services attorneys to assist nursing home residents, resolving insurance denials, advocating for resident rights, and securing appropriate discharge planning. There is no funding for these legal services, and

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MFJ’s Nursing Home Residents Project is, as far as we know, New York’s only legal services program for nursing home residents that is not a part of the Ombudsman Program.

6. **Require better investigation into character and competence of operators.**
Legislation should require the DOH and the Public Health and Health Planning Council to review complaints from facilities operated by applicants submitting certificates of need. The character and competence review should prevent operators of facilities with violations from acquiring additional facilities.

### III. Key Problems

1. **Residents’ integration with the community is illegally restricted.**

Residents’ rights to autonomy and independence are not limited to choices about their medical treatment. On the contrary, an essential part of a person-centered approach to care is to permit residents to enjoy activities outside of the nursing facility and to come and go without unnecessary restrictions. A person’s engagement in her community does not need to end simply because she lives in a nursing home. Indeed, the integration mandate of the Americans with Disabilities Act (ADA) and state and federal regulations implementing the NHRA, require that residents be given the right to continue or initiate new contacts with the community beyond the walls of the nursing home.

Community integration is especially important for nursing home residents, because residents live within a highly regimented and institutionalized setting. Life within a nursing facility can be dehumanizing, particularly when a resident is isolated from the outside world. Atul Gawande summarizes the sterilized nature of nursing home life in his book *Being Mortal*: “Our elderly are left with a controlled and supervised existence, a medically designed answer to unfixable problems, a life designed to be safe but empty of anything they care about.” Residents who call MFJ use a different word for Gawande’s “controlled and supervised existence.” They call it “prison.” But the imprisonment of people in institutions due to their disabilities was supposed to have stopped decades ago. New York must act to protect nursing home residents who want more than an empty existence.

##### A. Nursing homes institute day pass policies that foster residents’ seclusion and dependence.

In general, the “institutionalization” of individuals with disabilities is a centuries-long practice that typically refers to the removal of people with disabilities from mainstream society to treat and house them in segregated facilities. In the 1970s and 1980s, New York closed or downsized many of its state-run facilities. But many people with disabilities who might have previously lived in state-operated institutions now live in other segregated settings, including privately-owned nursing homes.

As detailed in MFJ’s recent report, *Imprisoned in Their Homes: How Nursing Homes’ Restrictive Day Pass Policies Violate Residents’ Right to Community Integration*, attached to this
testimony, nursing homes in New York are detaining residents in violation of federal and state law. Most nursing homes in New York require that a resident formally requests a “day pass” (also known as an “outside pass”), which the facility may or may not approve and issue, each time a resident wants to leave the nursing home. Nursing homes regularly require that day passes be issued for any short daytime excursion, as well as for longer, overnight trips. For example, a nursing home resident might need a day pass in order to simply eat lunch at a nearby restaurant with a visiting family member. Often, facility policies require a request for a pass be made several days in advance. Unless a resident requests and is granted a pass beforehand, she is not able to exit the home. Many nursing homes arbitrarily deny requests for passes or only grant “escorted passes,” which typically require that the resident be accompanied by a “responsible party” at all times.

As a result of overly restrictive day pass policies, nursing home residents end up isolated, unable to attend family functions, visit with friends, attend religious services, spend time outdoors or participate in community activities. They are stripped of their freedom, simply by virtue of their living in a nursing home.

Moreover, the arbitrary denial of passes disproportionately affects some of the most vulnerable residents, including those without friends or family who live nearby. An MFJ client, Ms. L, was denied day passes even though she could take Access-A-Ride alone. She wanted to visit family in the Bronx and Staten Island, each of which was two hours each way from her nursing home in the Rockaways. To have a family member sign her out would require eight hours of travel, making a day trip impossible. Access-A-Ride did not require Ms. L to travel with an escort, and the nursing home never articulated a medically sound justification. After litigation we filed on her behalf, Ms. L was allowed to go out, both in the neighborhood to get some fresh air and on longer trips. Without MFJ’s intervention, she would have been a prisoner in her home, isolated from friends and family, in violation of her rights as a nursing home resident. In addition to maintaining these community relationships, Ms. L noted that going out lifted her spirits because it gave her something to look forward to.

Day passes can also be critical in allowing residents to exercise their religious and civil rights. Several residents have complained to MFJ that their homes’ policies prevent them from attending prayers at their mosque or synagogue. Other residents have been denied passes to look at apartments so they could move back to the community, or to attend court dates to prevent eviction from apartments they intended to return to.

B. The DOH refuses to enforce resident rights to facilitate integration with the community.

New York State regulations assume that nursing home residents have the right to interact with the community. Pursuant to both the NHRA and New York regulations, every nursing home resident must be provided with “the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, consistent with the resident’s comprehensive assessment and plan of care.” To ensure the resident’s well-being, residents have the right to:

5 42 C.F.R. § 483.24; 10 NYCRR § 415.12.
• “A dignified existence, self-determination, respect, full recognition of the resident’s individuality, consideration and privacy in treatment and care for personal needs and communication with and access to persons and services inside and outside the facility.”

• “Exercise his or her civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, which shall not be infringed.”

• “Meet with, and participate in activities of social, religious and community groups at his or her discretion.”

These regulations clearly establish the right to leave the nursing facility.

New York regulations further emphasize self-determination, personal decision-making, individuality, and access to persons and services outside the facility. For example, New York regulations require nursing facilities to provide each resident with “considerate and respectful care designed to promote the resident's independence and dignity in the least restrictive environment commensurate with the resident's preference and physical and mental status.” Also, the facility’s environment must “maintain[] or enhance[] each resident’s dignity and respect in full recognition of his or her individuality.”

Full realization of these rights is not possible if the DOH refuses to enforce regulations allowing residents to participate in community activities of cultural, recreational, social, religious, or other personal significance. In Ms. L’s case, that’s exactly what the DOH did. When our advocacy with the nursing home was unsuccessful, we filed a complaint with the DOH regarding the nursing home’s violation of Ms. L’s rights to participate in community social and family events. We thought the case was simple and could be quickly resolved by a call from a DOH inspector. However, the DOH advised us by phone that a nursing home’s day pass decisions were “not something [the DOH] would override ever or dispute.”

The ADA prohibits unnecessary confinement of individuals with disabilities and the state is responsible for ensuring compliance by licensed facilities statewide. However, New York State has not acknowledged or taken any action to protect the rights of nursing home residents who are held against their will. This disturbing and widespread practice has received relatively little attention, despite its enormous impact on the lives of nursing home residents.

The law does not support residents’ incarceration, but the legislature must act to force DOH to support residents’ integration and the fullness of their lives.

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6 10 NYCRR 415.3.
7 Id.
8 Id.
9 Id.
10 10 NYCRR § 415.4.
11 10 NYCRR § 415.5.
2. Residents’ health and safety are being compromised by inappropriate involuntarily discharges from nursing homes.

The NHRA and state and federal implementing regulations provide for six reasons why a nursing home can involuntarily discharge a resident: (1) when it is necessary for the resident’s welfare (that is, the resident needs a higher level of care, such as an inpatient psychiatric unit); (2) when the resident’s health has sufficiently improved to no longer require a nursing home level of care; (3) when the safety of other individuals is endangered; (4) when the health of other individuals is endangered; (5) when the resident has failed to pay for services at the facility; and (6) when the facility is closing.\(^\text{12}\)

When a resident is given an involuntary discharge notice, she can request an appeal hearing from the DOH. At such a hearing, which is held at the facility before an administrative law judge, the burden is on the facility to prove (1) that the discharge is necessary and allowed under the regulations; and (2) the facility’s discharge plan is appropriate to accommodate the resident’s needs.\(^\text{13}\) Although residents are allowed to have counsel or someone else represent them in the hearing, few residents do.

Although no one comprehensively tracks involuntary discharge cases, the evidence that we have suggests that the most common reason proffered for involuntary discharge is that a resident’s health has sufficiently improved to no longer require a nursing home level of care. This could be a logical consequence of high quality care: A resident with a need for sub-acute rehabilitation may recover after therapy and no longer need a nursing home level of care. But those cases usually result in planned, voluntary discharges. The cases we see are different: We have noticed an increase in two types of involuntary discharges that should concern the Assembly: (1) residents who complete rehabilitation but would qualify for long-term nursing home placement; and (2) long-term residents of the facility whose health suddenly “improves,” according to the discharge notices, who are discharged to the intake center for the city’s homeless shelter system.

A. The DOH has failed to stop nursing homes from illegally discharging residents when their Medicare coverage ends.

Nursing homes across New York, like facilities across the country, are trying to increase revenue by maximizing their number of short-term rehabilitation patients and minimizing the number of long-term custodial care residents.\(^\text{14}\) Most short-term rehabilitation residents have Medicare, which pays a daily rate to facilities for up to 100 days. After that, the resident generally must pay from their own funds or have long-term care insurance, or, much more often, enroll in Medicaid to pay for long-term or “custodial” nursing home coverage. Medicaid pays about one-quarter of what Medicare pays.

\(^\text{12}\) 10 NYCRR § 415.3(h).
\(^\text{13}\) Id.
Nursing home beds in New York are dual-certified – every bed is approved for payment by Medicare or Medicaid. The law prohibits facilities from discriminating against a current resident because of the source of payment. That is, someone who is admitted with Medicare cannot be discharged because payment for their stay switches to a lower rate from Medicaid.

But that is exactly what is happening in facilities across New York. Nursing homes across the city (usually, but not exclusively, for-profit facilities) are telling our clients that the facility has no “long-term beds” available, so after the resident’s Medicare days are used up, the resident will be discharged. These facilities are taking advantage of residents and families who are unfamiliar with the law, overwhelmed by insurance issues, and dealing with stressful health and family matters.

The financial incentive for facilities to take rehabilitation patients is clear. But nursing homes are in both the rehabilitation business and the custodial care business. The law does not allow them to choose patients only until their Medicare runs out.

The Department of Health has refused to issue guidance to facilities reminding them of these legal obligations. Residents must be savvy enough to research the law themselves or contact an advocate at the same time they are focusing their energy on recovery. New Yorkers should not face the unnecessary stress of a discharge hearing or threat of discharge when dealing with health emergencies. The law is clear. The DOH needs to do its job. Facilities that are guilty of these abuses should face fines, and their operators should be prohibited from acquiring additional facilities.

B. DOH fails to stop nursing homes from illegally discharging long-term residents to homeless shelters

A homeless shelter is not an appropriate discharge location for a nursing home resident. Because shelter admission procedures were not designed for nursing home residents, there is no procedure in place for shelters to evaluate the appropriateness of a resident before the resident walks in, unless the resident agrees to be discharged to the shelter. But in many cases, the basic conditions in city shelters demonstrate how they are inappropriate discharge locations for nursing home residents. Homeless shelters are not medical facilities. Many are not accessible to people who use wheelchairs or have other mobility impairments. The very nursing home residents whose movement outside the nursing home is generally restricted are being discharged to shelters where they are required to leave for most of the day, have no assistance with activities of daily living, and must carry not just themselves but their belongings with them. This is inhumane, inappropriate, and, we believe, often illegal.

In 2016, at least 140 nursing home residents in New York City were discharged to homeless shelters. Probably many of those residents did not know their legal rights, but some who did were also discharged to shelters. DOH officials have failed to take any action to prevent additional shelter discharges.

15 10 NYCRR § 415.3(b)(3)-(5).
We recently represented a resident of a facility in Far Rockaway who was facing the threat of discharge to a shelter. The discharge notice alleged that the resident had failed to pay the facility and was therefore was going to be discharged to a shelter. In fact, our client’s insurance company had never stopped paying, and had even authorized continued payment to the facility after she was given the discharge notice. We appealed to the DOH and requested certain records from the facility documenting the alleged non-payment and other medical records. The facility failed to respond to our repeated requests for documents until the day before the hearing, when it withdrew the notice. The DOH sees that as a resolution. But before the threat of a shelter discharge was “resolved” the facility issued a frightening discharge notice, with no basis in fact, failed to comply with the laws regarding access to medical records or access to records prior to discharge hearings, and needlessly caused great emotional distress. It faced no consequences for its conduct.

Usually these shelter discharge cases are brought alleging the resident has improved sufficiently to no longer need a nursing home level of care. It is hard to imagine a situation in which a long-term resident’s health sufficiently improves for the resident to no longer need a nursing home level of care. In most cases, the facility has been billing Medicaid for a resident’s care up to the discharge date. One must wonder, then: How can the facility bill Medicaid for a nursing home level of care while also representing to the administrative law judge that the resident does not qualify for a nursing home level of care?

Similarly, we have received complaints from residents who have faced discharge to a shelter after the resident declined a discharge to an assisted living program in an adult home. Assisted Living Programs (ALP) require residents to need a “nursing home level of care” to qualify for admission. If the nursing home and the ALP agreed that the resident is appropriate for admission to an ALP requiring a nursing home level of care, how can a nursing home claim that the resident’s condition has sufficiently improved to no longer require a nursing home level of care? It seems that facilities are taking contradictory positions, and that DOH administrative law judges are letting it happen, to the detriment of residents.

These discharges have become so common that state regulators should immediately audit facilities’ medical and financial records regarding individuals discharged from nursing homes to shelters. Such an audit could uncover either violations of residents’ discharge rights or improper Medicaid reimbursement requests and Medicaid payments.

Nursing homes win many of these shelter discharge hearings, often because a resident is not given an equal opportunity to review the record or an advocate to make her case. But many times when an advocate represents a resident, the DOH’s administrative law judge orders the facility to do more appropriate discharge planning. While that may result in a better outcome than an inappropriate shelter discharge, it does not hold facilities accountable for issuing inappropriate notices. ALJs should be better educated about their responsibility, and should not shy away from ruling against facilities that fail to meet their burden.

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16 See 18 NYCRR § 494.4(c)(1).
3. Residents do not enjoy the rights afforded them by the 1987 federal Nursing Home Reform Act.

The NHRA directed nursing homes to provide person-centered care, guaranteeing a resident’s right “to participate in planning care and treatment or changes in care and treatment.”\(^{17}\) Furthermore, the NHRA’s implementing regulations clarified that a resident has the right to “a dignified existence, self-determination,” and the ability to “choose activities, schedules (including sleeping and waking times), health care and providers of health care services consistent with his or her interests, assessments, plan of care and other applicable provisions of this part.”\(^{18}\)

Thirty years after the reform law, these guarantees have yet to be fully realized. Most residents – long-term or short-term – are not able to live the “dignified existence” they want, or exercise the self-determination they did before entering the facility.

A. Facilities apply one-size-fits-all policies for administrative convenience rather than patient-centered care.

The centerpiece of the person-centered care approach codified in state and federal law is the care plan based on a resident’s unique experience, needs, and desires. The residents and family members who contact Mobilization for Justice have not experienced this person-centered approach that empowers them to make decisions about their care and life in the facility. Although the law guarantees residents the right to participate in care planning, including being “fully informed in advance about care and treatment and of any changes in that care or treatment that may affect the resident's well-being;”\(^{19}\) that is not our clients’ experience. Care plan meetings and decisions about residents often happen without residents present. In those situations, a staff member stops by the resident’s room to briefly update them on the outcome of the meeting. Residents tell us that sometimes these promised updates never come.

When residents are barred from participating in their care plan, the quality of their care, and their dignity, suffers. For example, one resident told us that for months, he was routinely woken up early in the morning for a medical test that could easily have happened later in the morning. Although the law explicitly guarantees him the right to choose his schedule, and he requested changing his schedule to one more suitable to his customary wake-up time, the nursing home ignored his preferences.

Person-centered care requires sufficient staffing, which at many New York nursing homes means more staffing. The Centers for Medicare and Medicaid Services recently published staffing data for New York’s nursing homes, based for the first time on auditable payroll information. The new data is clear that facilities are understaffed.\(^{20}\) More than 30 percent of New York nursing homes that complied with the new reporting requirements provided, on average, less than two

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\(^{17}\) 42 U.S.C. § 1396r(c)(1)(A)(i).

\(^{18}\) 42 C.F.R. § 483.10(f)(1).

\(^{19}\) 10 NYCRR § 415.3(e)(1)(iv).

\(^{20}\) See CMS, “PBJ Direct Care Staff” data set. Available at: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Direct-Care-Staff/92ri-abw3
hours per day of Certified Nursing Assistant care to each resident. Every week we hear from residents complaining of problems that could be solved with more staffing. When we visit facilities, we see residents waiting for meals or assistance with other personal care needs. When we try calling clients, we hear staff telling us to call back later when it might be less busy, or simply not answering the phone at all.

Low staffing levels mean residents have to wait for assistance, and they get shorter and less helpful explanations from overworked staff. Complex matters like insurance coverage for rehabilitation services are rarely explained in ways residents understand, often because the person doing the explaining does not understand the issue. This summer, for example, one of our clients, whose insurance plan stopped covering physical therapy, was given a notice by the facility saying her Medicare, which she does not have, had run out, and she needed to apply for Medicaid, which she already had.

Residents and their family members who want to review their medical records, or consult with doctors outside the facility about the resident’s care, frequently report roadblocks that violate state regulations. Facilities do not produce records in the required time period, and routinely and incorrectly tell indigent residents they must pay before they receive copies of their medical records. Care suffers when residents and their families cannot make timely, informed decisions.

### B. The DOH fails to ensure residents’ rights are protected.

The DOH must ensure that nursing homes comply with federal and state regulations. These regulations cover a range of topics and are intended to ensure the highest quality of care for residents. The DOH is supposed to ensure compliance with regulations by regularly inspecting facilities and investigating complaints and incidents reported by residents or third parties on behalf of residents. Yet the DOH fails to properly investigate resident complaints. A recent study by the U.S. Department of Health and Human Services found that, in 2015, New York failed to timely investigate two complaints alleging a resident’s immediate jeopardy and failed to timely investigate 976 other high-priority complaints. By the Inspector General’s measure, the DOH’s investigations continue to be untimely: In 2011, it timely investigated all immediate jeopardy complaints, but failed to timely investigate half as many high-priority complaints (448). An investigation by the New York State Comptroller in 2001 found that the DOH failed to properly investigate nearly half of all nursing home complaints. Sometimes the DOH conducted no investigation at all because it merely relied on the facility’s internal investigation. The report concluded that “the health and safety of nursing home residents are not being adequately protected.”

Not much has changed since 2001. Between 2007 and 2015, 79,804 complaints or incidents at nursing homes were reported. Of those, only 37,303 – less than half – were investigated by the

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24 Id. at Executive Summary.
DOH.\textsuperscript{25} Mobilization for Justice regularly assists nursing home residents in filing complaints and often finds that they are not investigated, or the DOH finds them to be unsubstantiated without even bothering to speak to the complaining resident.

Even if it does investigate and find a violation, the DOH fails to penalize nursing homes. Facilities therefore face no repercussions for some violations and are disincentivized to adhere to regulations that protect residents. A 2016 State Comptroller Report found that “[a]s a matter of policy, [the DOH] does not utilize the full array of enforcement actions available to it . . . choosing to not levy fines for well over 80 percent of the violations it cites.”\textsuperscript{26} The report notes that this “appear[s] to undermine the incentive that fines can have as a deterrent to deficient practices, as well as the sense of urgency for correcting the deficiencies, particularly in addressing cases of repeated non-compliance.”\textsuperscript{27}

The legislature should increase funding for enforcement so that complaints are handled more quickly and completely, and should require DOH to impose fines for violations, to improve the quality of care provided to residents.

\textbf{IV. Conclusion}

Mobilization for Justice thanks the Committee on Health and the Committee on Aging for holding this hearing. We are committed to helping the State develop and implement a stronger system to ensure people living in New York’s nursing homes are able to realize the Nursing Home Reform Act’s 30-year-old mandates. Those mandates are that all residents shall be able to maximize their quality of life, be treated with dignity and respect, and be integrated into the broader community, whether by appropriate discharge planning or by leaving the nursing home to participate in activities of their choice.

\textsuperscript{26} Id. at 7.
\textsuperscript{27} Id.